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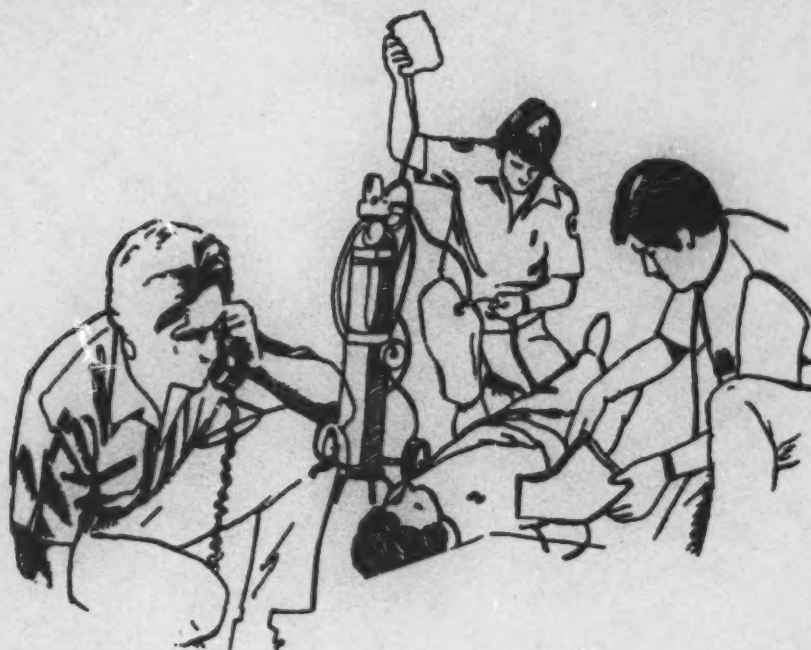
ABSTRACT

This report addresses comments and recommendations of parents of children with traumatic brain injury (TBI) as well as those of professionals. The report is in two sections: (1) What Parents Say about the Time of Injury; and (2) What Emergency Personnel Should Know. The first section presents quotes from five parents about reactions and experiences at the time of the child's accident. The following specific problems are then identified and associated recommendations offered: (1) delayed field time; (2) delayed or inadequate medical assessment and/or treatment; (3) inadequately trained first responder personnel; (4) disparity of trained staff and equipment at various facilities and related issues; (5) poor parental access to the child; (6) poor communication and lack of information; and (7) lack of knowledge and assistance in making technical/medical decisions. The second section includes professional comments and recommendations of the New York State Head Injury Council concerning first responders and emergency care. Recommendations address treatment at the accident scene (e.g., standardization of training and certification of Emergency Medical Technician) and treatment in the hospital emergency department (covering assessment, staff education, family involvement, and record collection and documentation). (DB)

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Us About Treating Children with Traumatic Brain Injury

By Betty Pleper, B.S. Ed., R.N., C.

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"In thinking back to the scene and immediately after my son's accident, I remember one of the EMTs standing there, saying, 'What do we do with him?' Now I know that they were talking about 'How do we get him transported?' (At the time this mother was terrified that the team did not know to handle her son's injuries.)

"A lot of damage is done to the parents before their children are in the hospital. You know, I had very good immediate triage care for him at the scene and transportation, very good people. but they need to remember that the injury does not stop with the person lying there, that the parents are an integral part of that."

"These EMTs -- the EMTs, the ambulance crews, the fire rescue people need to understand that not only is the person lying on the ground or in the water injured, but so are those parents and they need to be taken into consideration immediately -- they need to be trained to remember that."

Introduction: In October of 1989, the New York State Head Injury Association held a conference using consensus building processes in order to identify stressors and potentially helpful interventions for the parents of traumatically brain injured children. The conference was held as part of a research grant entitled Model Family-Professional Partnerships for Interventions for Children with Traumatic Brain Injury, which had been funded by the National Institute of Disability Rehabilitation Research.

It is important to understand at the outset how the nature of our qualitative research process affected our findings. The parents who told their stories at the consensus conference were asked specifically about stressors. There is probably no greater stressor than finding out -- or even seeing -- one's own child severely hurt. Therefore, in asking about stressors, we expect responses to deal with the negative, to what is wrong with services and systems. That is, in fact, important information for those who seek to improve services. However, it must be acknowledged because the following stories will not necessarily reflect the typical situation in emergency care. Furthermore, tributes are due to first responders, emergency personnel, and critical care professionals and paraprofessionals in hospitals who serve with technical skill and compassion night after night and day after day, sometimes under the most trying circumstances.

The first part of this report deals with the comments and recommendations of parents as they remembered their child's accident. The second part of this report reaches back to 1987 and includes professional comments and

recommendations as put forth in draft form by the New York State Head Injury Provider Council. The Council sought to address the issue of first responders and emergency care from a different perspective than parental stress, namely how that care and treatment impacts subsequent rehabilitation outcomes.

The format and content of the NYSHIA Provider Council white paper are remarkably in sync with parental observations and recommendations, indicating that many professionals are sensitive to parental stressors and indeed analyze similar situations in similar ways. Further, James Wasco, M.D., who oversees emergency services for a hospital system near Boston and is health editor for *Women's Day*, was invited to present cutting edge information and insight on this same topic at a professional conference convened under the NIDRR grant in November of 1990. His perceptions also support the concerns of parents and the general content put forth by rehabilitation providers in 1987. We like to think that this bodes well for "family-professional partnerships" in resolving some of the dilemmas in this area. We look forward to disseminating our findings to people who can help to make emergency and acute care services more responsive, not only to the needs of the patient, but also to the needs of the family.

Section I: What Parents Say About the Time of Injury

What's Wrong: Five Situations

Situation #1: One mother talked about her experience when her son was injured on the family's farm in an area of the state which is generally considered affluent. The problems this mother encountered were not limited to rural response time or other anticipated problems considered inherent in a "semi-rural" setting. Rather, the concerns she raises go to the heart of competent medical advice, medical assessment, turf issues in hospitals, informed consent, accessibility of care, and other important acute care issues.

"I did the wrong thing. I transported him myself. I picked him up, put him in the truck. I also think that responding to that, too, is when my son got to the hospital dealing with the emergency room staff. It's terribly stressful. I mean, there should be a better way at intake. I shouldn't have to think about what our hospitalization insurance policy is.

There was a medical team waiting at our local hospital. But, it was to our advantage that he had to be transferred. They didn't have a CAT scan there. Had he been treated at the local hospital, they would have performed brain surgery on him.

As it turned out, it was not needed when we got down to the medical center, so I'm just wondering when you have to make crucial decisions at that time, what are the patient's rights to know about the facts? Which is the liaison person that is going to help you, you know, sift through all of this information. I mean, if we had stayed at the local hospital, not knowing, I would have said,

"Yes, if this is what he needs, let's do it." But in the time of crisis, where do you get that other person, when life is at stake?"

This mother goes on to explain that in their case, their pediatrician was there and he advised them that their child needed to be transported to a major medical center with a CAT scan. Even with the support of a familiar and trusted physician, she remembers the situation as a horror story. Her pain and stress was not limited to the worry for her son; it was increased by the non-medical frustrations and lack of appropriate related social supports.

"Again, I think getting through that emergency room situation is a nightmare. There should be something available to families so that you are not fumbling through your purse to get this out and the other thing out. — Here we were going an hour down to the medical center. I didn't even have my pocketbook, so I didn't have the necessary tolls. I mean, it was little things. — And, along with that, we had to make a decision about a transfusion. We didn't want that, and yet it was done anyway. — We wanted our own blood given, and they just said, 'Not time.' So I don't know. At the time that was very stressful."

Later, in the process of describing stressors, the same mother returned to the time of medical crisis explaining that parents must at times be reduced to struggling to fill the survival needs of food, clothing and shelter for themselves in a strange place in order to be near their child.

"Because we are more than an hour from a medical facility, one of the stressors we had was we didn't have a place to stay. The hospital had a waiting room, but it seems to me there should be something available, either a list of hotels or something for families coming from a distance."

This situation is, of course, worsened when the family lives at greater distances, is not able to afford to stay over, cannot take leave from work, and needs to care for other children or relatives at home. Thus, a family's need will not be limited to finding safe or even affordable rooms near the child.

Situation #2: A wife whose husband's career is in the military described her son's injury. Some of her problems related to "military medicine;" others did not. Sometimes she seemed to assume that the quality of services is uneven and that others have similar problems in the community.

"Eighteen months ago my son had a bike accident. He hit the front end of a parked van at 35 miles an hour. Don't feel bad. Here I go, too." (In recounting her story, she is moved to tears and her remarks are directed to the other parents who have also broken down with their pain in telling what had happened to their sons and daughters.)

"He received an open depressed skull fracture. He is now 15. At the time, I had to deal with something different than a lot of other people do. I have to deal with the federal government — and I have to deal with the civilian world, too. The federal government does not receive — we active people do not receive the allocations that give us authorities that are worth a damn. My son

was up for almost 10 hours with an open, contaminated wound. The doctor at the hospital at our clinic turned to me with a skull x-ray in his hand and said, 'Does this look normal to you?'

I was triaging my son. We did not have personnel. I was cleaning up his blood. What he (the doctor) meant was, 'Was this a normal delivery? Or, were there forceps involved?' (The mother took the doctor's question to be an inquiry as to whether or not the son's skull was depressed before the accident.) I had to volunteer the information that he was a Caesarean section and there was nothing. That is not a normal skull x-ray.

He was then taken to what was considered one of the finest hospitals in the area, which is 15 miles down country roads to a larger city. In the meantime, he had spent 6 hours on a backboard with a surgical collar and chest wrap.

When we got to this larger hospital they said, 'Do you have a neurosurgeon of preference?' I'm sure every family keeps one. I have one. He is my next door neighbor."

The mother is using sarcasm to indicate that most people would not be able to respond to such a question affirmatively, and perhaps, are left feeling more anxious, inadequate, or vulnerable when asked.

'Insurance for the military is another story, but when we got to the Emergency Room at the trauma center they said, 'We are going to do a CAT scan and we will let you know.' Well, they did what they call a zip stitch. Never cleaned the wound. They stitched him up so he wouldn't bleed on their CAT scan. I still get upset.

He disappeared and came back, and this doctor in white walks toward me down the hallway and said, 'He is definitely an open depressed skull fracture. We are going to do surgery tomorrow afternoon.' We had been told nothing. All I knew (before this) was that my son was bleeding from the head. Scalp injuries bleed tremendously anyway.

I had no concept of what we were looking at. I stayed with him. My husband went home. I spent 57 hours in care with this kid. He was released to me 24 hours post-op, and I was supposed to handle this? I was scared to death."

This mother went from thinking -- or hoping -- that her son had suffered a scalp injury to finding out that her son's skull was virtually shattered; she said that the doctors told her they put it back together with "biological super glue." She said that the doctor told her that surgery was much more serious than anyone had first anticipated. Beyond that the surgeon communicated primarily the immediate condition of her son; he had "tolerated surgery well and was fine."

"We had only two follow-ups with the doctor because we are (military branch) and he said, 'Mrs. Jones, if you have any problems with this kid it will happen within the first year.' I automatically assume physiological, brain swelling, seizures, loss of strength, etc."

Eleven months later, my son decided that he was going to go off the edge. Violent. He was borderline homicidal/suicidal. Even the psychiatrists had no idea which was he going to do. We gave him a choice to either go into a private psychiatric hospital or be committed. We had no choice. It almost got to the point of domestic violence and we had no support."

This mother went on to explain in detail that it is not only dealing with the military world and the civilian community which has been so difficult, but also the need to deal first with medically oriented emergency care services, and, then, later, with the psychiatric establishment -- without the hint that the two (the injury and the psycho-behavioral problems) could be connected. **"Neither world is aware of what head trauma is - and what it needs at the onset."**

As seems to be the case with most parents known to the NYSHIA, this mother was given no information about potential non-acute sequelae which may follow traumatic brain injury, such as major emotional and behavioral problems. Follow-up neurological visits were not scheduled over time and there was no mechanism for inquiry into personality and behavioral changes or for referrals for evaluation/treatment if they do occur.

At another point, Mrs. Jones alluded to the financial considerations inherent in deciding where the patient should be treated. **"For us to stand around for 8 hours waiting to make a decision to transport him, whether it was financially feasible or not."** Her statement was left unfinished, stated more as a declaration of unbelief than as an explanation of anything. This commentary is interesting because many citizens assume that if the U.S. had a national health insurance policy, citizens would automatically have timely care of good quality; many further assume that this situation already exists in the military where there is an entitlement. In point of fact, the situation is vastly more complex.

Situation #3: A father who lives in Brooklyn described how his problems were compounded after his son's suicide attempt since his son was in foster care and he did not have custody.

"There was no accountability to me. -- At the time of the incident, an ambulance responded. Volunteer ambulance service which is not certified by the New York State Department of Health. EMTs, AEMTs were not certified. They didn't take their courses. They were actually on the rolls with the New York State Health Department that they were actively certified which they were not."

We got to the emergency room, were seen by unlicensed doctors in a life and death situation documented by the New York State Health Department, but they say he got adequate care. Sustained a cardiac arrest in the emergency room which has been covered up. They found no deficiencies in medical care only that the medical records were inadvertently altered."

Situation #4: Another father noted that he had no problems at all with the emergency care or transportation of his daughter who was critically injured in a boating accident. But it was the lack of support and communication in the hospital which was painful.

"I didn't question any doctors at all. My daughter was unconscious. The neurosurgeon in my town was not there. They got her to the ambulance. They took her to Erie. We followed about 10 minutes behind. When we arrived in Erie, and I didn't know if that girl was dead or alive.

They had her up in intensive care. All the machinery was put on that girl to keep her alive and the neurosurgeon checked in. I saw the neurosurgeon. Then I didn't see the man until a week later and he says, I suppose you would like to talk to me.'

Prior to that he said, 'If I have anything else to tell you, I will tell you,' so a week went by and this guy -- I never saw him. Here my girl is laying in intensive care in a coma. -- I was very uncomfortable with the fact that the doctor that was in charge of my daughter, the neurosurgeon, didn't even come and tell me what it was, but he told me, 'If I have anything to tell you I will get in touch with you.'

When I met him in the hallway, he says, 'I suppose you would like to talk to me.' I said, 'Yeah. It sure would be nice. I would like to know how my daughter is,' and he said, 'I don't have anything to tell you.'"

Situation #5: One mother described her experience by integrating some of the kinds of help she would have wanted.

'First of all, I feel that you definitely need somebody right there as soon as it happens who is knowledgeable and knows the ropes. -- Because when Nancy was brought to L.B. Hospital, they had to move her right away because they told me, 'She is going to die because we don't have the facilities to take care of her even overnight.' The doctors started playing Monopoly. 'Take her to this trauma center. No, take her to my trauma center. I had five doctors playing games with me. They couldn't tell me which one was better, which one she would make it to first.

When I finally had to make a decision, they wouldn't let me anywhere near her in the beginning, and then I come to find out that right in the beginning she was in a coma, and right in the beginning is when it really counts to hear familiar voices, familiar sounds, things like that.

They wouldn't let me hold her. They wouldn't let me go near her in the beginning until she was medically stable. Then when she was medically stable there was nobody to tell me, 'Make sure they do something to prevent foot drop,' because -- I mean, basic things like this. You need somebody there who knows the ropes.

I had a social worker that sat there and cried. I don't need that. I need somebody who is going to be supportive not somebody who is going to fall apart. You need somebody who has been through it or with other people, someone who knows what to look for."

Problems, Themes and Recommendations

In addition to the parent consensus conference (qualitative component of Model Family Professional Partnerships grant), a Family Questionnaire was sent and the results analyzed. Of the 242 respondents answering where the injured child was taken following the injury, only 10% said the child was taken to a trauma center; 85% said their children went directly to emergency departments at hospitals.

The children represented in our Questionnaire had severe injuries by many measures. Two hundred and nineteen children (219) were admitted with 82% of those responding that they were confined over 3 weeks. Two percent (2%) remain hospitalized and 14% of those responding are still in rehabilitation facilities.

The Questionnaire did not ask about experiences related to the time of actual injury, but we assume that the respondents to the survey research had similar experiences as those who had participated in our parent consensus conference. It should be noted that our parent meeting did not ask specifically about experiences at the time of injury, but asked only for major stressors as parents remembered them and as they presently experience them. (The other overriding question was to describe what would help and then rank their interventions.) Yet, every parent chose to describe the "time of accident" and the circumstances surrounding their receiving word of the child's injury as a major life stressor.

Some of the areas of concern to families and comments/recommendations which were implied or stated during our consensus conference are summarized below. Additional recommendations are incorporated from the professional consensus conference and the grant's advisory committee.

1. Delayed Field Time: Field time usually refers to "response" time, time on the scene and time in transport. Part of this problem is inherent in the wide diversity of our state's geography and demographics due to special difficulties involved in rural transportation over winding or bumpy roads, for example, or being tied up in city traffic. Sometimes it is because volunteers must be rounded up from various settings and then must travel themselves to a central location before they can set out for the accident scene. Sometimes, as stated throughout the narrative report of parent comments, the problem goes well beyond "response" and scene time; issues impacting decision-making in transporting to a facility are discussed in items 4 and 7.

Recommendation: Every Emergency Medical Service (ambulance and first response) should compile and publish the time required to reach 85% of the patients they see. This figure would provide the public with knowledge of how long the response time is likely to be and is more accurate than the "average" time for reaching the scene. If the public feels that the time is unacceptably high, citizens then have an opportunity to demand more resources for solving the problem.

2. Delayed or Inadequate Medical Assessment and/or Treatment: This problem is partly due to staff not understanding the full consequences of traumatic brain injury except for gross symptomatology, such as skull depression or loss of consciousness. If the injured child seems to be oriented in even the gross terms as found in the Glasgow Coma Scale, for example, he may be considered "okay."

While medical personnel are well trained in the dramatic signs and symptoms which may indicate that the brain is bleeding, for example, they seldom know about the less dramatic consequences (memory loss, confusion, problems with word finding and vision, emotional ups and downs, verbal outbursts, etc.) which can ruin the quality of one's life. Indeed, "minor" head injuries are seldom seen by emergency personnel as requiring any kind of follow-up or referral at all after a 24-48 hour "watch."

Recommendation: All emergency and acute medical and health care personnel should have training not only in administering the Glasgow Coma Scale but also in the most frequent sequelae of traumatic brain injury, both major and minor, "medical" and psychosocial. Videotapes can be made available for such purposes. Mechanisms should be developed to encourage such personnel to visit rehabilitation centers and to make available certain outcome information on specific patients they have treated. "Bridges" should be built so that rehabilitation personnel and emergency/acute care personnel have more access to each other and understand each other's missions better.

3. Inadequately Trained First Responder Personnel: The fact is that many first responders are inadequately trained, sometimes at least in part because they are volunteers who may work fulltime jobs and have other family and community responsibilities. Often these people are unpaid or underpaid, and they may lack time and funds for further training which is often at inconvenient times and in distant places.

Recommendation: Controversy surrounds the issue of whether or not the state should aim for all professional emergency care personnel with specific levels of training. It seems that the dual system of volunteer and paid responders is here to stay at least for the foreseeable future. Therefore, incentives should be put in place to build cooperation between various kinds and levels of emergency service provision. Cross training and peer review might be explored. Continuing education could involve a combination of independent study, supervised "Internships," correspondence courses, cross training with other groups, mobile team demonstrations, and hands-on experience under supervision and/or clinical practicums such as those used by the Regents College in the Bachelor of Nursing degree program.

Funding to individuals might feature the use of tax credits or tuition waivers in exchange for a given number of community service hours. Expenses for the county or state might come from user's fees, insurance, or designated funds such as surcharges on speeding or other motor vehicle related violations of the law.

4. Disparity of Trained Staff and Equipment at Various Facilities and Related Issues: The hospital or medical treatment clinic which is nearest to any given victim will not necessarily have a CAT scan, a neurosurgeon or an anesthetist available within minutes. However, occasional news reports bear witness to patients being transported to one hospital and then refused, transported to another which is not equipped to handle the injury, and then, perhaps, dying en route to yet a third hospital. Clearly there has to be a better way.

Recommendation: The Department of Health needs to continue efforts to designate major trauma centers, define who will be treated, and to work with medical organizations, individual professionals, and consumers to define minimal expectations for treatment in each setting. More use should be made of the electronic media to access consultancy and second opinions from experienced professionals as decision-making protocols in treatment.

5. Poor Access to One's Child: An assumption is made that the first order of business is saving the child's life and giving treatment which will stabilize him medically, preserve pre-accident capabilities, and prevent secondary complications. Parents agree with these goals. But a further assumption is implied that life saving treatment cannot be done with parents present, that they are emotional and get in the way. This is not always true. Some parents are more in control when they see what is happening. Some parents can be an enormous help in comforting or distracting the child or even in "disciplining" the child to facilitate required treatment.

Sometimes, in fact, there is *no one* with the child during various times in the emergency department; the anxieties of both parents and the child could be lessened by a sensitive nurse or doctor saying, "You can come in now while I write some orders at the desk." Further, some parents want to ride in the ambulance with their child. Some parents want to hold their child when death is imminent or has already occurred. Being deprived of final contact with the child seems to be a tremendous hurt for parents and if a decision can be made which will not compromise emergency care, the decision could mean the difference between a more normal parental response to great loss and anger, hurt or chronic grief which is carried as a burden throughout life.

6. Poor Communication and Lack of Information: Often parents have been stereotyped in literature as overanxious and overprotective. Clearly any human being will be anxious when a loved one has been injured and he feels that he or she cannot get information. Parents responding to our Family Questionnaire ranked having their questions answered, having explanations from professionals and having information on traumatic brain injury as primary needs. While some people may be able to rely on blind trust in this situation, it can be assumed that most will be decidedly nervous and many will fill the informational void with imagined scenarios.

Further, even when information is given, the timing of the communication, the tone of voice, the non-verbal signals which accompany the communication and the exact choice of words become important. Probably no emergency service responder, emergency department worker, or health care professional realizes that the words they utter as part of their job, perhaps in a hurry, will become immortalized forever and will be repeated for decades to come in various

forums and places. But that is exactly what happens. It is imperative that medical and health care workers learn how to talk to their patients and families just as they learn other skills.

Parents at our consensus conference indicated that the lack of information, the confusion in messages from various people, and the manner in which communication occurred were traumatizing for them. They seemed to be saying: we were hurt by being shunted aside, we were hurt by words we didn't understand, we were hurt by people telling us different things and by not knowing who was in charge and what our rights were. We did not know how to get comfort or technical information for ourselves.

Apparently these parents suffered the hurt and tried to tell themselves that it was okay, possibly even necessary, in order that their children receive good care. They indicated that they sought to identify with the personnel and to rationalize their actions and words. After all, emergency personnel and surgeons are busy saving lives; they are not supposed to be social workers. Parents seemed to be saying that perhaps these workers "couldn't function" if they let it "get to them, if they took it personally." It is as if parents had persuaded themselves, perhaps, that technical competence and sensitive communication could not coexist until they talked with each other about what they had experienced.

Whether or not the rationalized views of the family's trauma have amounted to a successful reframing of a traumatic experience or have lingered in some form to negatively affect subsequent relationships with health care workers is not known. In our conference parents seemed to want to talk about what had happened and how they had been treated. And, they wanted emergency personnel to know and remember that they had been injured, too.

Parents also seemed to be saying that they needed knowledge and advice about the nursing and rehabilitation care and treatment of their children. They wanted someone to tell them whether or not it was okay for the staff to use an x-ray every time a nasogastric tube was inserted, that terrible contractures of limbs could occur if preventative measures were not taken, that agitation may be a stage in recovery and is not necessarily "bad," and that their lives would be changed but that they could learn how to cope. Parents also wanted to have access to someone who might protect them "medically, financially and emotionally."

Recommendation: *In-Hospital Patient and Family Support Staff:* A clear cut line of communication and a commitment to family support is needed within the hospital. One person should be identified who will always be apprised of the patient's condition and "what is happening." This person should be responsible for communicating with the family and for being available to family members at designated times. Even when there is no change in the patient's condition, it is important to tell the family and to find out how they are doing. Hospitals can also help by supplying families with lists of private duty nurses, volunteers who are welcome in the hospital who may sit with the patient at bedside, safe and inexpensive places to stay, and by making lounges available to parents and assisting parents in making the long distance calls to their families at home.

Professional Education: Yet another approach to health care/family communication is practiced by Stanley Klein, Ph.D., Editor of *The Exceptional Parent Magazine*, who teaches health care professionals to understand the anxieties of parents, to respect their role as experts on their children, and to view them as partners. His courses and his writings cover everything from choice of words to non-verbal language and seating arrangements. Parents at our conference recommended that teaching emergency and acute care personnel how to interact with a traumatized and injured family should actually be part of the certification or recertification for these professionals. The parents present volunteered to help design and review such curriculum and offered to participate in inservices for emergency and hospital care practitioners.

The parents in our conference seemed to believe that if they could not get timely communication and sensitive support from designated medical and health treatment personnel, they needed and wanted it from someone else. They wanted "someone" available at the very beginning who could give them medical type information, emotional support, and practical guidance. This person should also be broadly knowledgeable about the financial and legal perils, other support services and about specialty and community referrals. They expressed a strong preference for someone who had "been there" or who had "been there with other families."

Trained Independent Family Support Workers: The NYSHIA envisioned this kind of person in designing its FACTS program (Family Advocacy, Counseling and Training Services) and presently operates family support programs in 5 areas of the state; the programs are grant funded. The FACTS staff person is available to families in person and by telephone. Although some record review, calls and letter writing are done on a family's behalf, the FACTS coordinator does not actively case manage, but rather trains the family in self advocacy and links them to a large body of specialty TBI information and both specialized and generic services primarily through referrals. Only one of the conference participants had this service available to her and indicated that it was, indeed, helpful.

An internal quality assurance survey conducted in 1989 and the results of our Family Questionnaire in 1990 (Model Family Professional Partnerships Interventions grant) show positive outcomes from the FACTS intervention. Findings from the Questionnaire show that 68% of the respondents found the written information helpful, 64% found the training or other information helpful, 73% found the emotional support helpful, and 70% thought that the FACTS program helped them to find and use community services. When these percentages are adjusted to exclude the respondents who said that any given item was not applicable, the percents are even higher, namely 86%, 75%, 87%, and 81% respectively. Further, 73% or almost 3 out of 4 respondents were contacted by the FACTS worker within a year of their child's injury which indicates a degree of timeliness especially given the difficulties inherent in an approach which is external to the delivery system (hospital, Department of Health, etc.)

The problems in delivering the support which NYSHIA's FACTS program has represented seem to revolve around the availability of funding for the program, and, perhaps, at times the reluctance of hospitals to make referrals outside of their facilities. (Our data from the Family Questionnaire demonstrate that 26% of our FACTS referrals came from professionals and hospitals.) At our parent conference, there was a lengthy discussion on how confidentiality could be protected and still be assured that parents are linked to appropriate supports, including the New York State Head Injury Association. All participants stated that they would have been pleased to sign a waiver of their rights to confidentiality in order to be linked to someone to help them. They felt that this opportunity should be available to all families. Two other devices mentioned in the conference which might facilitate early referral to an independent support staff person were: 1.) a state registry which would send a card out to every person injured as is currently done when an infant is born with a birth defect, and, 2.) a mandatory posting in the hospital itself at nursing stations and in lounges.

Parents also suggested that volunteers could be used. A trained, independent support person could call hospitals 2-3 times a week for referrals on a schedule just as reporters or police officers have a specific "beat" to cover. Whether paid staff or volunteers are used, it would be useful to find ways to work directly with hospitals. For example, it might be possible for all hospitals within a given region to meet together to discuss and agree upon the basic parameters for independent support worker involvement. Areas addressed at minimum would be: 1.) screening of staff or volunteers, 2.) training for staff or volunteers, 3.) parameters of counseling, 4.) treatment of confidentiality issues, 5.) interactions with hospital staff, and 6.) resolution of difficulties.

7. Lack of Knowledge and Assistance in Making Technical/Medical Decisions:

Parents remembered with anguish that they felt completely powerless in determining questions, such as "Where should the child be taken?" "Should the child be transferred and if so where?" "What equipment and services are crucial?" "How does one find a good neurosurgeon?" "How does one decide on one procedure over another?" "How does one know whether the child is receiving the appropriate kind of care?"

Recommendation: The Department of Health which is charged with designating trauma hospitals should explore (with input from professional groups and consumer groups) ways to provide timely assessment, second opinions, and independent professional review. Parents and professionals alike understand that resources must be used effectively. They want to know that decisions are made based upon sound assessment and patient medical need, however, and not irrelevant factors.

Section II: What the Emergency Responder Needs to Know

Introduction: There is an adage in nursing which says that "Discharge planning for a patient should begin at admission." This means that, generally speaking, when a patient has entered the hospital, it is assumed that he or she belongs in a different world and that with appropriate care and treatment, the person will return to that world. Therefore, staff will do everything within their power to return the patient to optimal functioning and to prepare the patient and family each day in every way for any alteration in function through such means as teaching new skills, promoting a positive attitude, adapting equipment and schedules, securing appropriate supplies and assistance at home, if necessary.

A corollary to "discharge begins at admission" might be "rehabilitation begins with injury." Of course, it is a given that what we think of as emergency medicine takes precedence and what we think of as "rehab" takes a back seat to life and death. Nevertheless, the two are more closely related than one might first think. What happens on the accident scene has negative or positive implications for rehabilitation.

For example, a person is pinned in a badly damaged auto. A well intentioned helper on the scene notices the profuse bleeding from the laceration of the victim's scalp and assumes from the expressions of pain and the deformity of the victim's leg that the leg is broken. That becomes the focus of his concern and intervention. He decides to wrest the victim from the car, perhaps guarding the leg, and in doing so, flexes the victim's neck. The victim ends up permanently paralyzed because a spinal cord injury was not apparent and the person trying to assist did not know enough to immobilize the neck as a precaution. Rehabilitation did not begin with injury; rather rehabilitation potential was forever lost to increased injury.

Further, in the present system there is very little communication between emergency or acute care providers and rehabilitation personnel. Acute care personnel, whether first responders, trauma surgeons, or nursing staff, often report that they experience a peculiar fragmentation from the present continuum of care in that they seldom receive feedback on patients. Some of these individuals have expressed interest in learning the outcomes in individual cases. Further, since such personnel have little information regarding rehabilitation philosophy, practice and outcomes, they often make assumptions that outcomes closely approximate the conditions they see. Conversely, rehabilitation providers struggle to find ways they can impact the early interventions of the patients with whom they subsequently work.

Ideally there would be a "bridge" between these providers. Education of emergency personnel would include, when possible, visits to rehabilitation facilities, inservices by rehabilitation personnel, and exposure to individuals who have made good recoveries. Education of acute care personnel should also emphasize that improvement takes place over a long period of time and often

at an uneven and unpredictable pace. Rehabilitation personnel could offer suggestions as to when certain kinds of rehabilitation related procedures could realistically be begun.

Background: The New York State Head Injury Association has long recognized that what happens at the accident scene and on the way to the hospital is of critical importance to a person's outcome. In fact, many physicians have referred to the time immediately following traumatic brain injury as "the golden hour." Further, the NYSHIA believes that discussion of emergency medicine should encompass admission to the hospital and the Intensive Care Unit experience as well.

Because of the impact of emergency and acute care upon the outcomes for people later seen in rehabilitation settings, the NYSHIA Provider Council addressed this topic early in its existence. On February 3, 1987, it was decided that any discussion of emergency and acute care for the person who has suffered traumatic brain injury should include: clarification and emphasis of the rehabilitation concept, clarification and emphasis of psychological and neuropsychological concepts, early intervention making use of rehabilitation principles and personnel, careful attention to the selection and use of medications, staff education, family education and family involvement, participation of social services personnel, support mechanisms beyond the acute treatment environment, and careful record-keeping.

Further, it was agreed that all phases of acute care, standards, guidelines and/or recommendations should be prefaced with a philosophical statement underscoring that:

- the patient who has suffered traumatic brain injury (TBI) has the potential for rehabilitation
- rehabilitation begins at the point of injury
- the quality of care from the moment of injury is important in preserving rehabilitation potential, averting unnecessary risk of increased disability, and in preparing the patient and significant others for the rehabilitation phase
- the care of the individual with TBI is so specific clinically and so significant economically that the entire field of head-injury requires special attention/incentive in order to develop: 1.) a comprehensive knowledge base, including research/evaluative components, 2.) specialized protocols for each discipline dealing with the patient and family, and, 3.) a comprehensive system of services which are presently associated with the treatment of spinal cord injuries
- the individual with TBI frequently requires care for many years; early preparation for long-term rehabilitation is important in facilitating realistic expectations for the patient and family, and in planning transitions from one level of care to another
- minor head injuries may present long-term problems, especially in areas of behavioral adaptation and cognitive functioning.

The Accident Scene

Background: Traditionally emergency service personnel have been trained to use the skills and resources they have available to save the lives and improve the chances of survival for victims of injury. However, the skills, training, availability of personnel, and resources (such as equipment) vary widely throughout the state. For example, "commercial" or proprietary ambulance personnel and first responders operating in a city of one million or more are required to be trained at Emergency Medical Technician (EMT) levels; others are not.

The various levels of training of emergency service responders may prevent effective acute care in many cases. For example, intravenous lines, airways, and medication administration are crucial in many cases. Yet only certain levels of emergency medical personnel can start intravenous (IV) lines or do esophageal and tracheal intubations. Therefore, lives may be lost if the personnel available do not have the skills or authority to initiate appropriate procedures.

The availability of certain equipment and even certain medications can also impact the care available at the scene and en route, and, therefore, the outcome of injury. For example, some patients with traumatic head injury experience generalized body seizures which deprive the brain of oxygen and stress the body systems. If these seizures become prolonged or occur one after the other (status epilepticus), the patient is in grave danger. In this situation, most medical protocols call for intravenous (IV) diazepam (Valium) followed by a loading dose of longer acting anticonvulsants (eg. phenytoin or phenobarbital).

Presently under existing regulations, unless an ambulance is hospital-based, there will be little chance that a controlled substance (diazepam, ie.) can be made available to arrest massive seizures. A regulatory change now in process is expected to make diazepam available to all certified ambulance services. To put the scope of the problem into perspective, nearly 30,000 basic EMTs would require training to start intravenous lines, however, and unless the skill is used frequently, it is not well maintained. It is generally considered more productive to shorten the time on the scene and transport quickly than to spend time starting IV lines.

Philosophy and Principles:

The treatment (or lack thereof) at the scene of the accident may directly affect the chances of survival, and may play a part in subsequent damage to the brain, and therefore, rehabilitation outcomes. *In general*, emergency protocols for traumatically head injured individuals call for:

- immobilization of the cervical spine
- good oxygenation of the brain, which may require an airway (Certain airways are problematic when, for example, the neck cannot be hyperextended and there is severe damage at the base of the skull.)
- ability to start a medication IV
- knowledge of Glasgow Coma Scale, Rancho Scale and similar tools
- assessment of neurological signs every 5 minutes

- immediate transport to a trauma center or a hospital with a trauma service where all Emergency Department staff are trained and a suitable treatment area is available where personnel can stabilize the patient.

Ideally the patient is taken to a designated trauma center. If this is not possible, the patient should be taken to a hospital with 24 hour access to a neurosurgeon or trauma surgeon, a CAT scanner, radiologist, anesthesiologist or Certified Registered Nurse Anesthesiologist, and an intensive care unit.

Recommendations:

- Training and monitoring in the use of the Prehospital Care Report.
- Development of standards of care for TBI management which include protocols for evacuation and transport, for availability of equipment and medications, etc.
- Standardization of training and certification of Emergency Medical Technician (EMT) personnel which requires mastery of specific content and acquisition/maintenance of specific skills relating to the acute treatment of traumatic head injury including:
 - training in use of a common assessment instrument (Children's Coma Score for non-verbal children, Glasgow Coma Scale)
 - training in insertion of various types of airways and ventilation techniques
 - training in establishing intravenous lines
 - training in the importance of documenting the position of the trauma victim by emergency responders
 - training in the importance of documenting any evidence of alcohol or substance abuse
 - education of all public, private and volunteer first responders including police, ambulance and fire companies in decision-making protocols regarding the appropriate use of regional trauma centers
 - education of public, private and volunteer first responders including police, ambulance and fire companies regarding neck injuries and minor head injury
- Training of emergency personnel should include the importance of periodic communications with family members or significant others on the scene or en route as conditions allow. Some degree of privacy should be afforded the patient and a family member, if medically possible, and if the patient dies, the family member should be given a chance to see, touch or hold the deceased if they wish. First responders could have cards available with the NYS-HIA telephone number or appropriate bereavement groups.
- Training in assessment should keep pace with research which indicates that various factors, along with the level of consciousness of the patient himself, may play an important part in assessing the severity of injury and the level of care needed, eg., one or more vital signs abnormal, the mechanism of injury, and the condition of other people in the vehicle. Therefore, it is important that these factors be taken into account in assessment of injury and carefully documented.

- Exploration of various funding mechanisms or incentives for the education of first responders and other emergency personnel through assessments/donations of auto insurance carriers, surcharges on related fines, state tax credits for certified volunteers, ie.

The Emergency Department

Background: In regards to emergency treatment at a hospital, primary attention must be given to the identification of head injury and the assessment as to whether or not the patient is to be treated or transported. When there are no clear cut guidelines, decisions may be made on a number of non-medical factors; a preprogrammed trauma center approach is recommended to avoid inappropriate criteria.

Several problems delineated in Head Injury in New York State, A Report to the Governor and Legislature, May 1986, are important considerations, namely the lack of designated trauma centers, the lack of assessment and care planning by skilled, interdisciplinary personnel who are trained to work as a team, the lack of uniform reporting, and inadequate collection and exchange of information.

Philosophy and Principles:

Although this area is fraught with controversy, some physicians believe that, in general, patients should receive as little of medications which cloud the sensorium (cognitive/expressive abilities) as possible. Physicians should have current knowledge regarding when anticonvulsants are indicated, what kind are useful, and how long they should be used, for example. The use of physical and chemical restraints should balance anticipated benefits with potential for harm; patient rights must be considered as well. Treatments and medications should be prescribed by physicians experienced in the treatment of traumatic head injury.

Staff should be alert for the potentiation of drugs which may otherwise be given in the presence of alcohol, illicit drugs, or other toxins which have been denied by the patient. Furthermore, when alcohol or drugs are clearly present, all symptoms may be assumed to be from those causes. A traumatic brain injury may not be considered as a possibility or contributing factor by the emergency staff. Thus, many head injuries go undiagnosed. Regardless of cause, impaired cognition may endanger the patient. Drug allergies, for example, may be denied by a patient whose memory is impaired and who cannot give a reliable medical history due to an undiagnosed head injury. Medical history, including cause of injury, drug use, and allergies, should be verified by a responsible person other than the patient whenever possible in cases of suspected head injury or other cognitive dysfunction.

The general environment should be one in which fast and competent action does not degenerate to thoughtlessness or disregard for human feelings. Staff should understand that lack of information, lack of access to loved ones, strange surroundings, unnecessary restraints, etc. may promote fear, anxiety and acting out by both the patient and family members. Language should be respectful and the demeanor of professionals should be as calm and open as circumstances allow.

The patient should not be left alone, and both the patient and family should be oriented to place and protocol and given time frames and access to at least one person who can offer current information and emotional support. Alternatives to physical and chemical restraints should be considered whenever appropriate. Likewise, the staff should be trained to understand that confusion and agitation may accompany head injury and be able to initiate appropriate procedures for patient/staff safety when necessary.

Summary of Recommendations

Assessment:

- Trained staff, including a neurosurgeon, should be available within 30 minutes.
- Staff should be trained to rule out traumatic head injury rather than look for gross signs and symptoms. (Head trauma is often overlooked in cases of multiple trauma.)
- Staff must be trained to seek third party verification of medical history, allergies and other crucial information given by patient self-report if there is likelihood of head injury. (Cognition, including memory, can be significantly impaired.)
- All patients who have symptoms associated with TBI, substance abuse or dementia should have screening for toxic substances, such as drug and alcohol since these cloud cognition and may potentiate other medication; confidentiality and rights issues need to be discussed and dealt with.
- Written hospital protocols should clearly define how decision-making is undertaken for treatment, stabilization and transfer.

Staff Education:

- If the hospital is an acute care trauma center, all appropriate personnel must be immediately available for treatment, including neurosurgical intervention.
- If the hospital has protocols to stabilize and transfer severely injured patients, the personnel available on a 24 hour basis must be capable of approved procedures and be in communication with the regional trauma center which will be receiving the patient.
- Emergency department personnel should be required to see the videotape, *Minor Head Trauma: When Problems Remain* (available from National Head Injury Foundation) as an inservice educational program; patients should have an opportunity to see the videotape as well.
- All staff treating acute injury should be aware of the latest developments in the field of head trauma, including controversial areas, such as induced barbiturate coma and common misinterpretations in skull series.

- Staff should understand the appropriate roles of specialists and seek consultancy as indicated.
- Staff should be educated to the psychological needs of both the patient and his family and should act accordingly to the extent possible.

Family Involvement:

- The triage nurse or other designated person should call someone **for the family** at the earliest possible moment. This person may be designated by social services, nursing or family life services and may be a hospital employee or a specially trained individual from community groups such as the NYSHIA.
- The family support worker or staff person should prepare the family for how the patient will look, explain the machinery being used, etc. and should accompany the family member during the initial visit after the injury or after the initial treatment/surgery. This support staff person may also function to explain procedures and interpret medical information to the family or another liaison person may fill this role.
- The family should be asked if clergy will be helpful, and, if so, the clergy person of their choice should be called.
- The family should be provided with a way to contact a designated liaison so that they may receive appropriate information as they need it and as it becomes available. The family should always know the name and how to contact the physician directly responsible for the patient's care. They should also know the names of each physician and the names, titles and functions of key staff so that they understand who to approach for what.
- The family's privacy should be respected as much as possible and staff should demonstrate sensitivity to both the patient (whether conscious or not) and to the family. The patient's condition should not be discussed in front of the patient unless, when appropriate, the patient is included in the conversation. Language should be chosen to express quiet confidence and alleviate anxiety. Although information should be given in simplified form, prognoses should not be made. Terms such as "vegetable" and "complete recovery" should not be used.
- Medical and patient/family psychological need and not staff convenience should determine the amount of access which a family has to the patient.
- The family or significant others accompanying the patient or the patient himself, when appropriate, should be given community resources such as a NYSHIA hospital card with the Family Helpline toll-free number.
- Patients who have sustained minor head injury should be offered an opportunity to see the patient-teaching videotape, *"The Unseen Injury; Minor Head Trauma"* (available from NHIF) before they are released from the hospital.

Record Collection and Documentation:

- Hospital staff should be trained in use of the Pre-Hospital Care Report (which is designed to capture important information regarding the use of safety belts, ambulance time en route, etc.) and should request additional information, such as: position of the victim at the accident scene, condition of others in the vehicle, and evidence of alcohol or substance abuse.
- There should be intensive exploration of a reporting system which would link a patient and/or family to appropriate services very soon after injury while assuring patient confidentiality. This might take the form of a registry or a third party notification system, for example.
- Explore the use of a Head Injury or Trauma Registry system. Although there are many advantages to a registry system, there is also some concern about the possible misuse of information. Such anxieties might be alleviated by contracting with a statewide not for profit agency which is not affiliated with state regulatory agencies having jurisdiction over health providers and which is not a direct care provider of rehabilitation services. This agency would observe strict patient confidentiality measures and protocols; only statistical data would be made available to most other agencies and to the public from the records.

- End -